See related meeting report on pg 2701 and review on pg 2726

EDITORIAL

Dermatology Quality of Life Instruments: Sorting Out the Quagmire

The field of dermatology can take credit for improving the quality of patients' lives. Many skin conditions affect patients in a multidimensional manner, ranging from emotional to social interactions, symptoms, and functional impairment. An example of one such skin condition is psoriasis, which has been shown to affect quality of life to an extent similar to that seen in other chronic diseases such as cancer, arthritis, hypertension, heart disease, diabetes, and depression (Rapp *et al.*, 1999). Individuals with psoriasis report feeling self-conscious about their appearance, and they may have a poor self-image. John Updike devoted a chapter, "At War with My Skin," to psoriasis in *Self-Consciousness* (Updike, 1980). He wrote, "Strategies of concealment ramify, and self-examination is endless"—the patient is continually inventing ways to hide the symptoms. Patients may experience symptoms such as itching and pain to the point that the basic daily functions of walking and sleeping are affected.

Quantifying the quality of life impact of skin conditions has been a relatively recent effort, stemming from a movement throughout medical science to capture the outcomes of intervention. Generic quality of life measures have been used by the medical community to measure the quality of life impact of general medical problems. For skin conditions, investigators have begun to use generic quality of life measures such as the Medical Outcome Study, Short Form (SF)-36 (Ware and Sherbourne, 1992) and SF-12 (Ware *et al.*, 1996), the Nottingham Health Profile (McEwen and McKenna, 1996), and the Sickness Impact Profile (Bergner *et al.*, 1981).

Many skin-specific quality of life measures have now been developed, one of the first being the Dermatology Life Quality Index (DLQI), developed in the United Kingdom in 1994 (Finlay and Khan, 1994). There are currently 11 skin-specific quality of life measures that pertain to adults, as found by the Working Group on Core Measures of the Burden of Skin Diseases (VanBeek *et al.*, 2007). Although these generic measures have been tested rigorously for psychometric properties, it has become evident to researchers that they do not necessarily capture issues that are specific to patients with skin disease.

Even more sensitive than skin-specific quality of life measures are disease-specific measures, which are designed to capture issues related to the disease that even skin-specific instruments cannot. For instance, the RosaQoL (Nicholson *et al.*, 2007), a recently published rosacea-specific quality of life instrument, captures such topics as avoiding certain foods or drinks and frequency of flushing. These issues are not posed in skin-specific quality of life measures because they do not pertain to all skin conditions. As a result, disease-specific measures are generally even more sensitive to changes in disease status.

An additional problem with these quality of life measures found by the Working Group on Core Measures of the Burden of Skin Diseases and by Both *et al.* (2007, this issue) is that there is a lack of standardization in definitions, conceptualizations, and psychometric testing. Although there is consensus that quality of life incorporates the perception of physical symptoms, effects on daily role function, and psychological impact, there is much disagreement and confusion about precise definitions, with researchers often using the same term (quality of life) to mean very different things. Moreover, widely varying procedures have been used in the initial development of quality of life measures for skin disease. The amount and quality of psychometric testing and validation also differ widely across instruments. Finally, an awareness of cultural differences is crucial when instruments are developed outside the country where the instrument is to be used. For instance, the Working Group on Core Measures of the Burden of Skin Diseases reported fewer than half of the instruments that they evaluated were initially developed in the United States. Instruments developed in other countries,

Journal of Investigative Dermatology (2007), **127**, 2695–2696.
doi:10.1038/sj.jid.5701176

such as the United Kingdom, may have implications for the appropriateness of the wording of specific items and thus may have limited applicability in the United States and vice versa. There is a need for domestic application and testing of those instruments developed outside the country of usage.

Both *et al*. (2007, this issue) have taken a first step toward evaluating the generic quality of life instruments applied to dermatology, as well as the dermatology-specific quality of life measures. Their criteria for evaluation were adapted from existing guidelines and included a conceptual and measurement model, reliability, validity, responsiveness, item functioning, meaning of scores, administrative burden, respondent burden, and availability of alternative forms and of cultural and language adaptations. Using these criteria, they were able to make several recommendations regarding the best instruments to use. This approach paves the way for future applications.

As more therapies are developed for skin disease, there will be a need for highly sensitive instruments to demonstrate responsiveness in quality of life, and the most sensitive instruments will be disease-specific. Although Both *et al*. (2007) did not evaluate disease-specific instruments, the Working Group found 15 for adults and 2 for children. With an increasing need for disease-specific measures, more investigators will be required to develop such instruments. The criteria applied by Both *et al*. will set the stage for the expectations for these new instruments.

Journals should consider adopting these criteria for papers submitted for publication that describe new instruments. However, to expect that each new instrument will fulfill all 12 of the criteria outlined by Both *et al*. may be unrealistic. I have thus proposed a division into minimal criteria, for newly developed instruments, and necessary criteria, which an instrument must further demonstrate to gain full credence and acceptability.

Minimal criteria for new instruments:

- Validity (content and construct)
- Interpretability (comparative data in different clinical populations)
- Reliability (internal consistency using Cronbach's alpha and retest reliability using an intraclass coefficient)
- Structure (using factor analysis or item response theory)
- Responsiveness
- Brief response burden
- Acceptable administrative burden

Necessary criteria to establish an instrument:

- Interpretability (minimal clinically important difference)
- Floor and ceiling effects
- Having been tested for alternative forms of administration
- For translated instruments, having been translated according to guidelines

This division of criteria is based on one person's experience, and obviously it must be evaluated in a consensus setting by others in the field. Please join the discussion.

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